Crafting the Body

Erin Stewart

Introduction

Hi, hi there. So, I originally made this art/writing project in 2017, a.k.a. some time ago. I wrote it for a format which now seems sadly defunct, Medium Series, which I guess was meant to be kind of like a Snapchat or Instagram story but maybe more wordy? Hosted on medium.com, I think it was a short-lived attempt to grab market share/financial viability. You can't make Medium Series any more, or easily access them, but I was able to track down the original (which is lucky otherwise it would be lost media). You can access it on tablet or mobile devices only, at this link: https://shorturl.at/WX4Y6
Or via the QR code below.

It has been a long time since 2017. I have acquired a small collection of new diagnoses since I originally wrote it (sleep apnoea, autism, and Ehlers Danlos Syndrome). Plus, there is a whole, ongoing pandemic. Nonetheless, the body is a pretty timeless concept, so I've only lightly edited the original content. Mostly to point out additional issues with 23andme that *were* apparent at the time but I felt like I could skip over.

I hope you enjoy this little project in its zine form. It's possible that it was always meant to be a zine, it just took a little while to find its proper home.

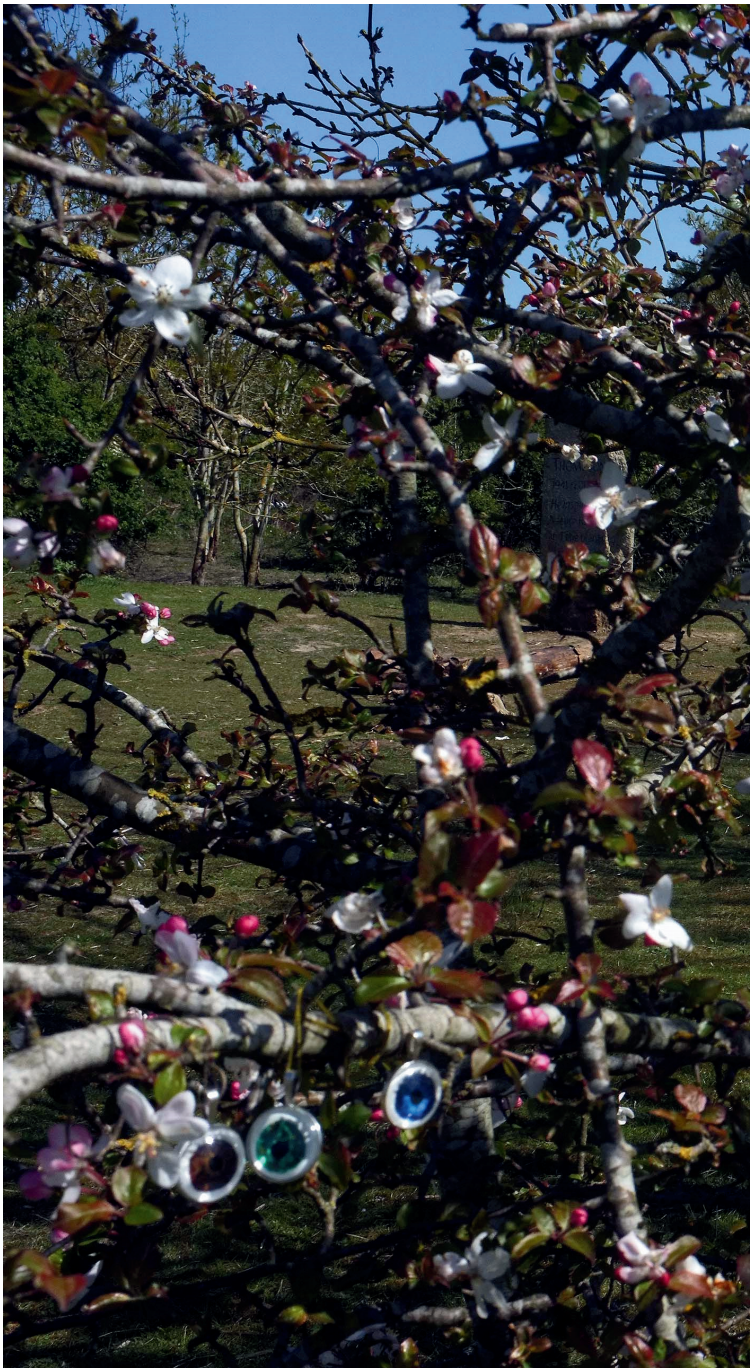
♥ From Erin
June 2025

The body is our general medium for having a world.

Maurice Merleau-Ponty

Everyone has a body. Perhaps it's also true that everyone *is* a body. It's the means through which we access life — it's the source of our senses, it is the space in which we exist — and (apart from possibilities surrounding the soul or other kinds of transcendent ways our self could manifest) it defines our personality, memories, thoughts, and creations through the dense neural networks that comprise our brain. The body structures our experiences, giving us all kinds of sensations, allowing us movement, realising the self. There is no life independent of the body.

For cerebral people, this can be hard to get your head around (*pun intended*). Often, I feel like I'm just a floating head, or pair of eyes which loom over the world. How embarrassing that our important work, our very existence, is contingent on something as base and animal as the movement of air, the pressured pumping of blood, the laboured ooze of digestion...



Heart Felt

(The puns are always intended)

Despite the centrality of the body, its workings are largely mysterious. Knowing stuff about the body is reserved for a highly specialised few. And even then, the body is so complex that different types of inquiry are separated out. An expert in neurology — the brain — might not know all that much about the heart, or the bones, or the eyes, or the skin, or the kidneys, or the teeth, and so on. The body is very close to hand/it is the hand/it is us, and yet understanding it is a faraway venture.

I have a heart. When I had pericarditis (a painful but ultimately harmless inflammation of the sac around the heart), I saw it beat on a monitor through ultrasound technology (an echocardiogram). I heard it. Sometimes I hear my pulse through the bones of my ears, but it's as much a tactile sensation as an auditory one. I heard my heart through a speaker system rather than through my bones. The sound was a bit like diving into a swimming pool.

This is the closest I've come to understanding my heart. I've never seen a heart in real life, only in pictures, in diagrams, on monitors.
I decided to create my own rendering of a 3D heart, made with felt. It's not accurate (there's silver sparkles and golden veins and if your heart looked anything like it, you'd be in a lot of trouble), but I can hold it, squeeze it. I used techniques I've known since I was a child to make it. I wanted to get closer to the heart by going through a process of externalising it, turning it into a cartoonish rendering, and reconciling it with the familiar.

And yet, I can't shake the thought: I don't know my own heart.

HEAD
cranium

EYES
oculi

MOUTH
cavum oris

NECK
collum

CHEST
thorax

GUTS
abdomen

GROIN
inguinal canals

KNEES
articulatio genera

FEET
pedibus

TOES
digiti pedis

Our bodies are our worlds.
Our bodies are medical artefacts.

cognizant
reason
cohere
mental
cerebral
astute
articulate
thought
system
meaning
lucid

The brain is a singular organ but with two hemispheres. There is the left side of the brain and the right side of the brain. The two are connected by a dense bundle of neural fibres known as the corpus callosum, which enables communication between the hemispheres.

Brains tend to be lateralised, meaning that one side usually dominates performing certain tasks over the other. You've probably heard about it: the left side is great at language and logical thinking and cubes; the right side is good at being super-creative and interesting and swirly.

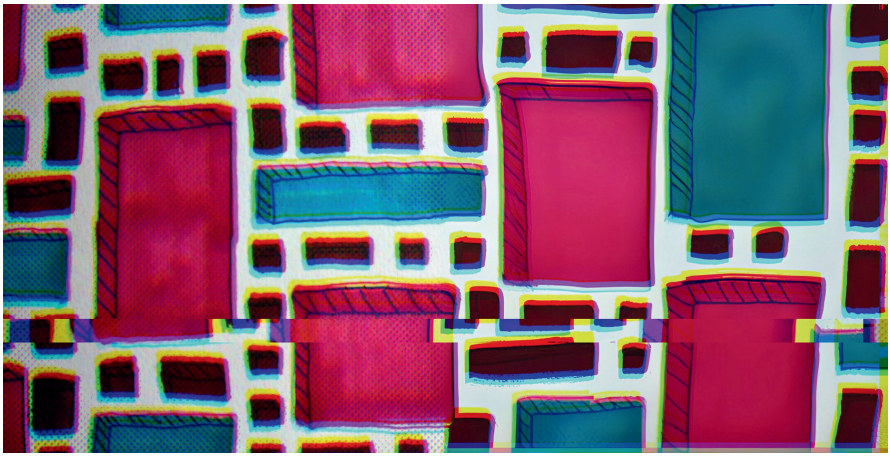
Usually when lateralisation is spoken about in pop psychology, people tend to overplay the dominance of one hemisphere over the other for different tasks. Dominance is a preference or a tendency for performing certain tasks on one side or the other, it doesn't mean that the right side of the brain is sitting dormant while you add up the total of your shopping bill. You're all lit up.

And while the right hemisphere is associated with creative flashes of insight, the left brain lets you tell stories. And I think that's pretty creative too? The left hemisphere gets a rep for being boring and worrying too much, but that's a massive simplification of what it does.

You are not left-brained or right-brained. You are more complicated than that. Your brain is full.

His wound gives him his narrative power.

Arthur W. Frank



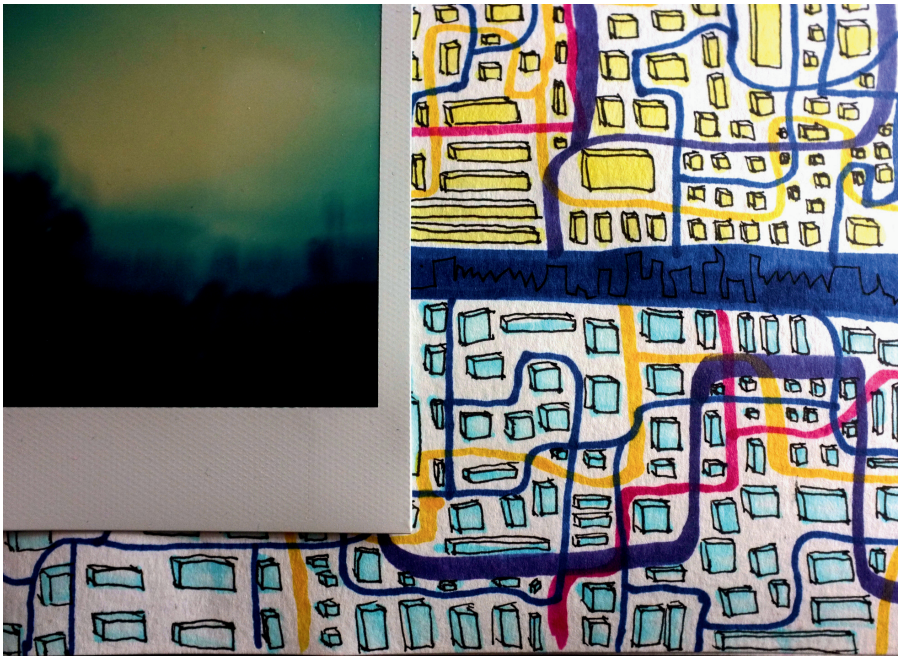
If I could change one thing about my experience of health, it would be fatigue. My fatigue is an oscillating kind of thing, it comes and goes. When it's very bad it becomes near-impossible to engage in life. I don't work with zest, I can barely listen to other people, my brain feels starchy and inflexible. On the worst days, I'm housebound. My life is prone to derailment and disruption of varying degrees.

There are some particular frustrations of fatigue which have more to do with how it is received by others and less to do with the fatigue itself.

People confuse fatigue with tiredness. Just as they confuse depression with sadness, migraines with headaches, anxiety with nervousness, and so on. Everyone has experiences that are analogous with fatigue when they've been working hard, or stressed, or sleep-deprived. But fatigue is on another level. You wake up feeling like a liquid, and the day doesn't usually get much better from there.

Another problem is that even though you feel liquid, you look solid. People might notice your weary eyes and slouching posture, but you might not look ill per se. I don't tend to find that people are very understanding about the struggle of fatigue ("everyone is tired") and moreover, when I have it I don't tend to find myself with sufficient energy to explain it, or even decide if I want to explain it. Instead, the limited stores of energy I have is geared toward getting through the day and trying to pretend that getting through the day isn't a monumental task.

Trying to figure out what causes fatigue, what makes it better or worse, reminds me of Thorndike's "Puzzle Box" psychology experiment. He had this box he locked a cat inside (psychology is historically very mean to animals). The box had a door but in order to open it, the cat would have to push a lever. To incentivise getting out, Thorndike put some tasty food outside the door. Not knowing how to get out, the cats would just use random strategies until they accidentally hit the lever. It seems like they eventually figured out the connection between the lever and the open door, but in a nonlinear, random kind of way. I've gotten out of the box a few times now and I have some ideas about what the lever could be, but mostly I feel like a flailing cat.



Having these sorts of confusions gets to me, even though over time I find myself becoming more accepting of my fatigue and my consequent limitations. It doesn't really help to fight against the body in my experience. And so, if fighting doesn't help, maybe there's something to find out in the experience of fatigue itself?

Of course, I would like to manage my fatigue better and feel it less, but I think as well, when you live with a chronic problem such as this, it can be useful to figure out how to relate to it in such a way that it could actually become a source of power. I don't really know how you do that exactly. This is ongoing work is both disrupted and shaped by necessary rest breaks.

For a start though, I take a lot of comfort from Johanna Hedva's "Sick Woman Theory" essay, which argues that sickness is an experience that is capable of political mobilisation. Specifically, we can work towards a politics of caring for oneself, and for others.

It's important to me that fatigue is seen as a serious, embodied, pervasive experience which doesn't need a name or a quantified data point to warrant compassion or to be seen as real. It's important to me that a person's value isn't tied to their undisrupted capacity to work. It's also important to me that bodily vulnerability in forms such as (and not limited to) fatigue can be a means to fixing the world. And here, as Hedva argues, fixing the world has little to do with making symptoms better and everything to do with creating the kind of society where people are cared about, regardless of how chronic, how indefinable, how inconvenient, inconsistent, and/or invisible their problems are.

My fatigue is nebulous and strange. I approach it as a scientific problem, as something that can be solved medically, as something to be rid of. I've not given up that hope in those things, but simultaneously, I see that my fatigue has a social meaning. I'm trying to give up the shame of it, and seeing it as a thing that's "wrong" with me. I'm trying to see my body in a bigger context where it can speak to something about compassion, respect, and care.

more lactose intolerant in the morning
breakfast not most important meal
black inside racial appropriation
peanut butter
tension in hips
you are your brain
manic switch
hypothyroid symptoms
early signs chest infection
hydrocortisone
how many grams in 900ml of icecream
BMR
how to block train noise
type 2 narcolepsy
adrenal glands
can you move during rem sleep
vat cake biscuits
nightshade
fasting glucose 3.7
people who feel better without breakfast
diabulimia
thrush if you're glamorous,
athlete's foot if you're not
tremor
fat greyhound
extreme fatigue sleeping all the time
mallomars
shelf life of lsd
chipped beef
high apetite
chest bruise
anaphalaxis
temperature regulation
how does a cane work
ring size
quantified self
invisible illness enamel pins
slang up the yin yang origin
mens shirts
this is a voice
orwell shot in neck
sebaceous cyst
sudden mole on hand
mthfr mutation
selective mutism
nhs private prescription
weighted blanket
can't swallow
how to unblock ears
ataxia
is adhd neurological
how to manage ruminations
how much does a weeks worth of food cost in vietnam
milo does not mix properly
whole30 diet
heads show us what you got
dreams of people with schizophrenia
swollen neck left side
difference between muscle knot and lymph node
boots eye test voucher
tonsil stones
designer glasses
cheap glasses
dyspraxia
why am i squinting my eyes
what is a simple partial seizure
cure chronic sinusitis
better off dead podcast
flight into health
gluten causes sore joints
overamping
effect of low barometric pressure
writers tears
definition disability
diabetes insipidus
how to get used to whiskey
semicolon tattoos
do tonsil crypts heal
do 3 year olds need a nap
naproxen
cereal conspiracy kellog stop masturbation
4 of pentacles health
water pik
what causes tonsil stones

I've tended to have an uneasy relationship with those online health forums where users talk about their experiences of illness. I think it's useful for information to be disseminated in accessible forms. For a lot of people, seeing a doctor is difficult. Or doctors may not know very much about their particular set of experiences, or might hold quite stigmatising beliefs about it. The danger of non-experts giving medical advice is somewhat concerning, although the reason I tend to cringe is more about the place illness seems to hold in these discussions. It's almost like some forums are alters to illnesses. People list their diagnoses and medications in their signatures. They have complete medical histories starting from generations ago.

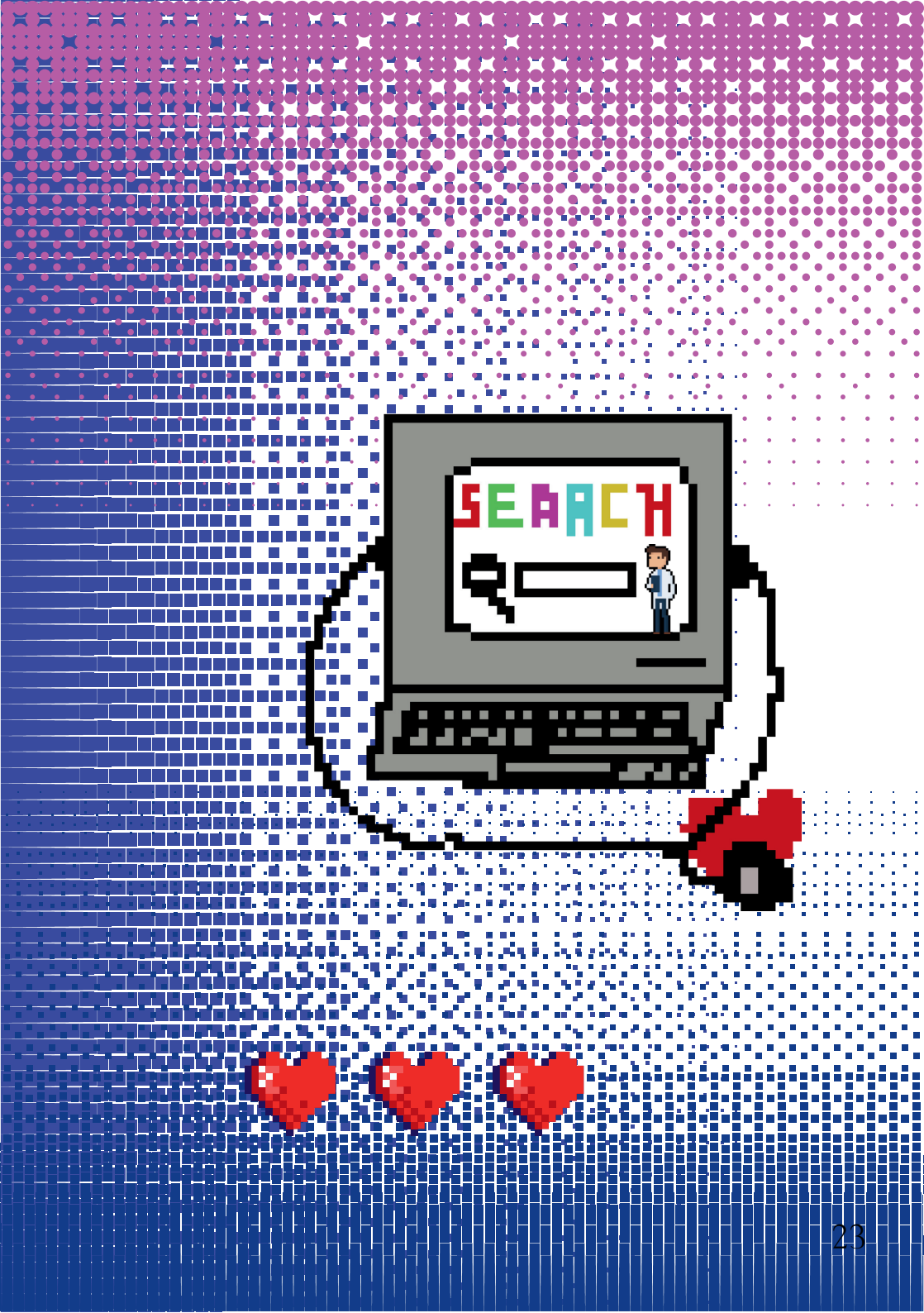
Of course, I cringe because I see myself in these users. There is a pull to centre oneself on one's sickness if one is sick. You make investigations, you try to figure out what's wrong and how to feel better. The danger is being pulled into obsession; the potential power is in traversing complex material about the body and figuring out a hypothesis or story that might help you.

Like the online forum, the Google search is fraught. Every sensation becomes a symptom of cancer; and yet, each search holds potential to claim information about your body, your self.

I went through my Google search history in the six months before April, 2017. There's a lot related to the body.

I think it's most accurate to think of my search history as a record of my curiosity on body-related matters. Some of the curiosity is self-driven. Over that six month period of time I've dealt with shoulder/neck pain, tonsil stones (ugh, so much ugh), sinus/hayfever issues, a weird blip in my thyroid function (it randomly went a little underactive), mental health stuff, fatigue, a need to update my glasses prescription, as well as other, more minor, sensations that I felt the need to Google and that more or less resolved themselves. More than I expected, it turns out that my curiosity about the body is also stimulated by the random stuff I read and watched which had nothing to do with what was going on in my life. I also dislike cereal and knew that the internet would vindicate me in my ongoing discussions about that.

The body comes up in my searches a lot. The Google search is evidently a mode through which I understand my own and others' bodies. It's almost embarrassing to share how much I search about it because I think it reflects some degree of obsession. But at the same time, I'm interested in the way in which these searches allow me to master my wounds and empathise with others'; and to understand what's going on with bodies as a non-expert (even if the information is simplified, anecdotal, inaccurate, etc.). It constitutes a grappling with what bodily experiences mean and a commitment to that flawed, ad hoc process.


SEARCH

Walking twenty-five miles, or even running up the stairs and back, suddenly seemed pointless, since, without the steps being counted and registered, what use were they?

David Sedaris

When I leave the house, I usually have my phone with me. As I walk around, the phone's pedometer captures my steps (although I question how accurate the data really is). If I turn on the location settings (I usually leave it off, partly because being geolocated is spooky and mostly because it's a huge drain on the battery), my phone tracks where I am. When I notice something pretty, or interesting, I take a photo with my phone. And thus, my phone has become an inaccurate and irregular medium of my body — what I see, and where and how I move.

When I went to export my steps data from my phone, it required some degree of techy know-how. I had to use the app in developer mode and investigate downloads which would allow me to obtain a .csv file. Then, once I got the .csv file, it looked like garbage. After some manipulation, I realised that it only contained steps information for a few months, and that the information was super granular, as in, an entry was made for every spurt of continuous walking, whether that be two steps or two thousand. It wasn't workable. I ended up having to manually enter steps data into a spreadsheet. I decided to go with my average number of steps per week throughout 2016 (information that the app provides in pretty, user-friendly colours, but doesn't allow you to systematically export), because 52 data points seemed like enough.

It strikes me that these steps are ours, but the apps don't necessarily make it easy for us to procure this information into convenient forms. It's a strange violation, to be producing data that I have very limited access to. Who owns our data is the stuff of ongoing dispute and investigation, both in legal and ethical terms.* In my case, Samsung (which made both the app I used as well as my phone) is the gatekeeper to a set of data points that say something about the life I lead when I'm outside my home.

I wanted this data in the first place to visualise this life outside. The following image shows the average number of steps I took each week in 2016 mapped against what I saw and thought to photograph.

It's a kind of diary of my body. Like all diaries, it's limited, inaccurate, and ignores swathes of detail. And yet, seeing a year of sights and movements laid out in front of me like that is really neat.

I didn't want to include numbers in this visualisation because it's distracting. What's interesting to me is the changing of the seasons and the relationships between peaks and troughs, and between level of activity and seeing.

* Self-tracking by Nefus & Neff is a really interesting investigation of how people use tracking data as well as questions of ownership of that data.

LETS
ADORE
SUN IN SPLENDO
LOUGH
ROAD
THE BUTTON QUEEN

In 2013, I was intrigued by the idea of mapping my own genome through 23andme, a service where users send their spit to a lab and are told about their ancestry, their risk factors for certain diseases, and random information about their body which they likely already know like whether they have wet or dry earwax and what they feel about coriander. I signed up and they, too, told me about myself.

The website is user friendly in terms of providing a selection of results. I can't say that the information I got was earth-shattering. On some inarticulate level I think I was expecting to find some crucial bit of information about myself that would lend meaning to my body and my life. What really happened was that I was offered a set of probabilities for developing various conditions, probabilities that lack meaning without context and that hardly provide a reliable insight into my future. Alas.

More concerningly, the fact that my genomic data exists in the world creates an issues of privacy and ethics. Who owns this data? I have recently (in 2025) deleted it from 23andme, and they say they have honoured this deletion. How can I know for sure? The company is now bankrupt and attempting to sell itself off. Who will be the custodian of all this genetic information in the future? Will they sell it on and on?

Can my genome be used to deny me health or death insurance? Could it be used for some nefarious, pseudo-scientific, eugenic aim? What problems have I gotten my body into as a result of my insatiable curiosity about it?

Before I deleted it, 23andme provided me with raw genome data in the form of a text file, which you can download.

If you read the text file as a non-geneticist layperson, it doesn't make sense. It's just a series of letters and numbers and spaces. You may recognise base pairs (some combination of two Gs, As, Cs, and Ts), but you probably won't know what it designates. And then, even if you knew what it all meant, most entries lack meaning on their own. There is no one gene that is an obvious marker for most conditions or traits. It's sets of genes, and relationships between those genes, as well as non-genetic and epigenetic factors that shape our health and bodies.

It's a slippery thing, to understand the body on a genetic level, which is what makes genetics such a complex kind of inquiry where developments are exciting but answers scarce.

I wanted to visualise my genome in a way that captured something of its relational quality while also both protecting my privacy and accepting that the information in there doesn't have to hold any meaning beyond the fact that it's a conceptual approach to understanding the self rather than something concrete and definitive.

So I made a quilt.

I got my raw 23andme file, and represented the average base pair over a collection of them with a different pretty colour. There were enough of these colours to make a whole big quilt!

From a perspective of generating scientific insights into my genome, the quilt is completely meaningless. You can't see my risk of heart disease or what my eye colour most likely is or where my ancestors are from. Nonetheless, it is still a representation of what's in there. It's a way of imagining the body's genes without expecting it to provide clear answers.

Life is about rhythm. We vibrate, our hearts are pumping blood, we are a rhythm machine, that's what we are.

Mickey Hart

Misophonia is the hatred of certain sounds. There are particular sounds that grate some people to the point of physical discomfort, rage, and panic.
I could list all the sounds that I dislike, but I'd prefer instead to tell you about a sound I like: the sound of trains.

The reason is rhythm. If I can feel a steady rhythm in my body, I know I'll be okay.
Comforting sounds, I think, combine senses. I like the sound, and I also like the tactile feeling I associate the sound with. The train is a good example, I like the feeling of being rocked and I associate the sound with that feeling. When I've been very distressed, I've found it comforting to go on a long train ride.

I made this audio file (link and QR code below) to pay homage to the rhythm of trains. I recorded a London Underground train (at Marylebone station) and put in some music. The featured music is from the_Free Music Archive. The first is "Peaceful Mind" by Borrtex and"Gaslight Demon" by Dilating Times.

https://shorturl.at/p6ywM

When I bought a tennis ball as a way to massage my own neck, I didn't have room in my bag for it. I carried it home. I squeezed it in my hands. It had a good amount of firmness, it didn't collapse under my grip like a stress ball, but I could also feel that I was having an impact. I tossed it in the air and caught it again. The sound it made was super satisfying as was the feeling of catching it to a regular beat. I liked having the tennis ball around.

There's a certain tactile pleasantness associated with objects that you can play with rhythmically.

I fashioned this contraption out of a kilt pin and two rubber balls. It is bouncy, which is fun. But mostly I seem to unhook and hook the pin from itself, and the rubber provides a fun resistance, it makes the task both more difficult and more satisfying.

Bubble wrap is safe music, it's like snapping joints into place, and putting things in order.

I have bipolar, which is really a disorder of balance, I think. Oscillations in energy, in feeling, in enthusiasms, in rhythm. It tends to be too much or too little, one way or the other. Finding the middle ground is an act of continual recalibration. For me, it started with the trial and error of taking the medication. And then it was about intellectual and emotional intention, trying to take notice when things were pulling in one direction or the other, and trying to correct it without overcorrecting.

I think lessons like these — ongoing lessons that make up the major themes of your life — are reiterated constantly. Maybe after awhile someone like me could live a balanced life out of habit. That's not been my experience though, at least not yet. I always have to consider it and I can only hope to get it right at a greater frequency than I have in the past.

There's a certain point, I found, where I wanted to reiterate this lesson of balance through the body. I was drawn to roller derby, I developed the tiny muscles in your ankles which make your foot stable when it's your only support and it's rolling on wheels. I don't do roller derby anymore (I'm too accident-prone) but I enjoyed learning the skills involved. You watch someone more adept do a move (turning a corner, turning around, stopping quickly, weaving through cones, and so on) and you break it down into components and work for hours putting them together.

"Sometimes your body is the last to know," one of my instructors said. Sometimes you understand everything before you can really put it into place. You have to keep going over the knowledge again and again until it becomes embodied.

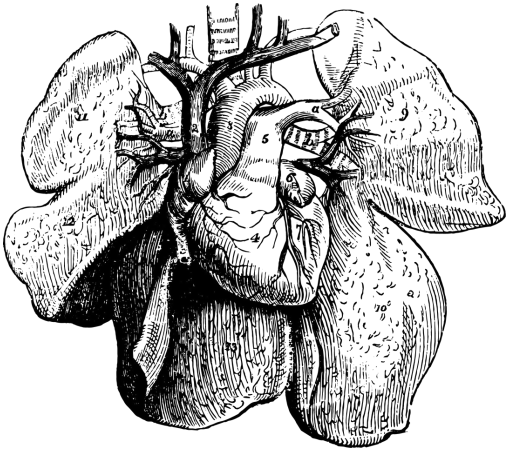
I don't feel like it was a coincidence that I was drawn to a sport which is essentially about practicing physical balance in rough conditions. It's an apt metaphor for my efforts to master some of the trickier points of my own life.

I went to a physio because I have a lot of shoulder pain. Among other comments, the physio offered this: “you have the back of a PhD student”.

Professions are embodied. The writer, the student, the desk worker builds a mighty hump, an arc with their back. In my research I've found that the best you can do is have an ergonomic set-up and take breaks and do activities that stretch your spine out backwards (backstroke, perhaps, but nobody at the pool ever does backstroke), but it's a hard fight to postural alignment.

When I think of my cavernous back, I also think of my father, who for many years as a self-employed gasfitter had a layer of silicon glue coating his hands. I think of my maternal grandfather, a tree feller, who had a trunk fall on him and spent the rest of his life with very cold hands. I once read about a florist who always noticed dirt under her fingernails. I think about the callouses associated with playing musical instruments, holding down buttons and strings. I think of public professions where people could expect to be photographed or filmed at any time and so feel they must maintain constant neatness.

Our jobs describe a set of activities we do over and over and the repetition marks us.



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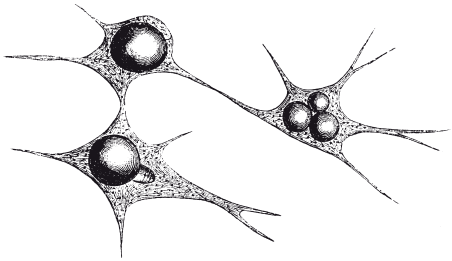

This was really an experiment in representing and thinking about the body — particularly my body — from a range of different perspectives. How do you come to know the body when you don't have a medical degree? How might my bodily difficulties be powerful? How does measuring the body change our experience of it? What role does rhythm play?

Contact

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